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Perceptions and beliefs of adults with cystic fibrosis about lung transplantation

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Aims Whilst lung transplantation has raised the prospect of prolonged survival and improved quality of life for CF patients with end stage lung disease, some patients die on the waiting list as a result of late listing. This study explores the beliefs of adults with CF that may influence their decision to be referred for transplantation.
Methods 8 non-transplanted CF adults (aged 18-32, FEV_1 23-59%) were interviewed. The audiotaped interviews were analysed using a phenomenological approach.
Results 9 sub-themes were identified and organized into three main categories: trying to lead a normal life, deteriorating health and a lack of knowledge.
The coping strategies that patients have developed had a large impact on their beliefs about transplantation. Participants using avoidance and denial saw transplantation as a last resort, they distanced themselves from other CF patients to avoid dealing with the 'bad part' of having CF. Conversely, participants who were frequently admitted and had friends with CF had seen the two faces of transplantation – success and failure. As their quality of life deteriorated, these participants began to incorporate transplantation into their thoughts for the future.
The importance of peer relationships in terms of shaping patients beliefs about lung transplantation was evident. As a consequence of increased patient segregation to reduce the risk of cross-infection and the increased use of home intravenous antibiotic therapy, the opportunity for patients to share information / experiences is likely to diminish.
Conclusion To assist a patient in their decision-making process health care professionals should identify the patient's coping strategy and consider providing information about lung transplantation earlier in the course of their disease.

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Deliberate self-harm and suicide in adults, and parents of children, with CF: a national survey of the experiences and training needs of the multi-disciplinary team

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Aims: Chronic illness and depression are strongly linked, combining to increase risk of deliberate self-harm and suicide. Within the medical field, misunderstandings are known to arise from a lack of formal management structures in the workplace and training. In CF care, confiding relationships between staff and patients often develop over time and there is real potential for issues of DSH or suicidal ideation to be communicated. This study aimed to survey CF teams' experiences and to collate views on management and training needs.
Methods: Staff from 33 paediatric and 23 adult, UK CF centres completed and returned 108 postal questionnaires (63 paediatric; 45 adult).
Results: 16% of respondents from paediatric and 80% from adult centres, experienced DSH (cutting or poisoning), in parents and patients respectively. A further 25% and 18% encountered actual suicide in these groups. Only 18% of staff felt that they received adequate support following DSH, and 12% following suicides, with the remainder believing support to be unnecessary. With regards to management and training needs, 66% did not feel confident about or were unsure of, responding to patients/parents who expressed suicidal ideation with 63% stating that they had not been taught signs of DSH. 38% felt that further training was required and 75% believed that the entire CF team should receive this.
Conclusions: Results suggest that whilst CF teams' experiences of DSH and suicide are relatively low and well-managed, there remain some training needs. It is suggested that the Team psychosocial professional has an important role to play in addressing these.

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What can a psychological service offer patients diagnosed in adulthood?

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CF diagnosed in adulthood has short and long-term psychological effects on individuals and their families[1]. These include: diverse emotional grief-type reactions, increased awareness of death, feelings of confusion, intrusion and isolation, impact on identity, lifestyle and personal relationships. In the RACFU, 7.5% of patients received CF diagnosis in adulthood. Despite being in good physical heath and having relatively good QoL, this group comprised almost 10% of referrals to psychology over an 11-month period (N=33).
Psychological interviews found that many patients presented with anxiety and low mood over diagnosis and prognosis. Common issues around health anxiety, isolation and misinformation were also expressed, but were discrepant from the Team's perceptions. QoL data from 47.6% of adult diagnosed patients showed lower scores on the 'Concerns for Future', 'Career' and 'Interpersonal Relationships' domains than those obtained on the 'Social Functioning', 'Physical Functioning' and 'Body Image' domains.
Psychosocial factors pertaining to late-diagnosis were also expressed by team members. These included: difficulties arising from haphazard and delayed diagnoses, patients' increased likelihood of being on the periphery of clinics and reduced contact with the Team.
This paper discusses these presenting problems in more detail and considers how the psychosocial needs of patients diagnosed in adulthood can be met through: routine post-diagnosis psychosocial assessment, psychological screening and increasing Team awareness and support.
[1]Widerman E et al (Eds), *"Now that I have CF" Information for men and women diagnosed as adults*. Solvay Pharmaceuticals 2004.

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Children's roles during consultations at Cystic Fibrosis clinics

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Aim: The aim of this paper is to examine the role of children during consultations at cystic fibrosis (CF) outpatient clinics. The need to consult children about their health and to view them as active participants in their health care has been highlighted by advocates of children's rights over the past fifteen years (UN, 1999; Alderson & Mongomery 1996; Sartain et al. 2000). However, there is little known about how to involve children during consultations in ways that accommodate their particular concerns about their health and wellbeing. ***Methods:*** 32 children aged 6 to 14 years, and their parents participated in tape-recorded interviews. Data were also collected by participant observation at outpatient clinics with a subset of 21 children. Data were collected and analysed concurrently using a method of constant comparison, and theoretical sampling was used to further explore and develop emergent themes. Discourse analysis was applied to clinic conversations. ***Results***: The conduct of consultations involved parents, children and health care professionals each taking on specific roles and identities consistent with Strong's (1979) description of the 'ceremonial order' of clinic. The social form of consultations privileged parents' accounts leaving children marginalised from contributing to conversations about their health. In assessing and advising about CF health, professionals used a biomedical language focusing on the clinical status of children's physical health and parents were found to accommodate this language in order to contribute to decisions about their children's health care. This language was of little relevance to the concerns of children and to the meanings they attached to being healthy in their daily lives. ***Conclusion***: The findings highlight a need to acknowledge children's social position as active participants in their health care and to accommodate their perspectives and concerns using child-centred approaches to consultations involving collaboration between children, parents and health care professionals.